A novel approach from critical care to home in regional Far North Queensland

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Summary
In July 2023, senior nurses in the Cairns Hospital Paediatric Unit were notified of a neonate being

returned to our local special care unit with the intention of memory making with his family and

ultimate compassionate extubation. The small regional paediatric nursing team, worked closely with interdisciplinary specialist services across the state, to ensure the family were well supported from their return to Cairns. Memory making was undertaken with the family and a plan for a compassionate extubation was articulated. Aware that this had previously been undertaken in hospice settings and actually in the home by other palliative care teams, the paediatric nurses raised this as a possibility for this family and in agreement with the coroner's office, a plan was initiated to take the baby home and extubate him there. The baby was taken home with the support of the medical, nursing and neonatal teams and his extubation took place when his family were ready. The baby surprised everyone and breathed spontaneously and over the subsequent 66 hours, a core group of paediatric nurses, with the remote assistance and support of the Paediatric Palliative Care Service, supported the family at home until their little one peacefully passed away in the arms of his parents, surrounded by love. For this process to occur in a regional setting demonstrates the level of commitment and collaboration that the team had in ensuring a high standard of holistic compassionate and family centred care for the family. The team truly worked in partnership with the family in meeting their specific needs and there are many accreditation standards that can be referenced to formalise this activity. Additionally, the teamwork that occurred between the neonatal and paediatric teams, with the tertiary centre and also the coroner's office led to an almost seamless process coming to fruition. The family wished for their baby to meet his extended family at home, (especially his fur siblings) and this is what the work of the nursing team in particular allowed to happen. The staff involved with this process, but especially the paediatric nursing team are exceptionally proud of the work they accomplished alongside the family and hope their experience can encourage other staff to think creatively in providing truly holistic care.

Jul 2023
Implementation sites
Cairns Hospital and Health Service

Partnerships

Key dates

Queensland Children's Health, Office of the State Coroner, Queensland Ambulance Service, Cairns Palliative Care Services

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Aim

This short venture aimed to bridge the gap between an existing paediatric palliative care service model which has worked well in previous years, and the specific and the unique needs of a family preparing for the compassionate extubation and subsequent death of their newborn.

Benefits

Due to the rare nature of this event, there is no quantifiable data to be obtained, apart from the achievement that the compassionate extubation of a neonate in the home has never been provided in Queensland by a team that is not in a NICU or PICU team.

Background

Providing paediatric palliative care in a regional centre can often be a challenging yet rewarding experience as access to paediatric specific palliative care services is limited. The thought of a child or infant reaching the end of their life can be confronting to many health care professionals, many who choose not to be involved. Within the paediatric unit, a core group of nurses firmly believe that infants, children, and young people within our district, should not be compromised during the end of their life, simply because of the limited resources available locally.

Solutions Implemented

An individualised, holistic family approach to care was implemented. The considerations and wishes of the family were able to be met with a creative and unique approach to care provision. The baby was taken home for his very end of life cares, supported by a step-up model of nursing care. Willing members of the paediatric nursing team availed themselves to coordinate and provide paediatric appropriate palliative care in the home and worked closely with the statewide paediatric palliative care service (PPCS) based in Brisbane. This model was undertaken with the relevant line manager approval and ensured that appropriate care was provided, as close to home as possible, and in line with the wishes of the family.

Evaluation and Results

There were many small successes and opportunities for learning during this experience for the nursing team although we have no formal data to offer. However, the main achievement and outcome is nothing to do with data, statistics or other Key Performance Indicators. It is that simply this activity was the right thing to do for the infant and his family.

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